

Living with Endometriosis

A qualitative exploration of women's perceptions and experiences of diagnosis, supports and treatment options in Ireland.

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INTRODUCTION

Endometriosis is an incurable chronic condition associated with debilitating pain and subfertility, which affects over 155,000 women in Ireland, for whom diagnosis may take up to nine years. In March 2022, the Department of Health launched the first Women's Health Action Plan 2022-2023, which includes the establishment of two specialist endometriosis services nationally. This study, undertaken in 2021, examined the perceptions and experiences of women with endometriosis regarding the diagnosis, support and treatment options available in Ireland with a view to informing health service development.

OBJECTIVE

“To gain an understanding of women's perceptions and experiences of diagnosis, supports and treatment options in Ireland for managing endometriosis, with a view to informing health service development.

METHODOLOGY

A qualitative study design with purposeful recruitment strategy was adopted. The study comprised of twenty semi-structured, online interviews with women with a medical diagnosis of endometriosis and experience of the Irish healthcare system and draws on the data of seven interviews. The data was analysed thematically using Reflexive Thematic Analysis.

RESULTS

Four themes were identified in the data:

(1) Dismissive/Unsupportive Attitudes which discouraged women from engaging with healthcare.

"People just seem to think that they know what that is (like) for every woman and I think they sometimes think well I get my period and I'm grand so can you just not handle the pain?"

(2) Lack of Knowledge and Education among general practitioners and women with symptoms.

(3) Delayed Diagnosis.

"Period pains shouldn't be debilitating, and they should understand that that's not normal and it shouldn't take as long as it does for diagnosis"...

(4) Inadequate Specialist Health Services.

Findings highlight the varied and protracted routes to diagnosis and treatment experienced by participants, and their medical and embodied knowledge of the condition and health service pathways.

DISCUSSION

This study is valuable as there is very little Irish literature on living with endometriosis and is unique in providing evidence regarding support and treatment options from a patient perspective. From the data a clear consensus was formed regarding supports and treatment options that are available in Ireland for managing endometriosis; the lack of support, information and adequate treatment, the need for specialised care and the differences between accessing private and public care.

CONCLUSION & RECOMMENDATIONS

This timely qualitative study presents the experiential insights of 20 women with endometriosis.

Recommendations:

- Development of specialised centres for endometriosis diagnosis and management in Ireland.
- Development of specialised centres must be informed by the experiential knowledge of women living with endometriosis.
- Moving towards a patient-centred multidisciplinary model of care.
- Reduced diagnosis time.
- Increased endometriosis education and awareness for healthcare practitioners, patients, and the public.